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ABSTRACT

The manual describes development of a personal growth and peer support group for parents of developmentally delayed or disabled children which was designed to help parents adjust expectations about their infant or young child and to accommodate the handicap. Initial decisions regarding leader and participant characteristics and frequency and content of meetings are considered. Objectives, materials, and approaches used in six meetings are presented. The meetings covered the following topics: different parent expectations, discipline and child development, reactions to the child's diagnosis, realistic goals for the children, effects on the rest of the family, and future considerations. Appendixes include sample questionnaires and meeting evaluation forms. (CL)

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A PEER SUPPORT AND PERSONAL GROWTH GROUP FOR PARENTS WITH A CHILD WHO IS DEVELOPMENTALLY DISABLED OR DELAYED

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Phyllis Jackson and Elizabeth Hill of the Virginia Beach Infant Stimulation Program first suggested to me the need for this kind of group. They arranged the initial information-gathering session with the parents of their Infant Stimulation Program, where we asked the parents to tell us their major concerns about their disabled child. This provided the topics for the later sessions. Phyllis attended every meeting, and helped wherever she was needed (even with babysitting). Bernadene Wallace, who herself has a handicapped child, helped plan and coordinate the meetings. Bernie's intuitive "having-been-there" sense about what the parents needed was invaluable. Judy Keller made some helpful suggestions about planning the group, based on her own experience leading groups. Dr. Douglas Gregory, a developmental pediatrician at the Portsmouth Naval Regional Medical Center, gave generously of his time as a guest at Meeting #4. His expertise and caring made the discussion of "setting realistic goals" a big success. I am also very grateful to all the siblings and parents who were guests at Meetings #5 and #6, respectively. I don't think anyone could have been more inspirational to the group. Finally, much thanks to Patti Field and Debbie Grane for their time in editing this manual.

FOREWORD

This manual is intended to document efforts to design a personal growth and peer support group for parents of developmentally delayed or disabled children, in order to assist other professionals who wish to undertake a similar group. As Case Manager of Virginia Beach Mental Retardation/Developmental Disabilities Programs, I conducted such a group from March 1980 until January 1981. The comments from parents about how much they gained from the group prompted the writing of this manual. It provides an opportunity for other professionals to adapt a program from this experience to suit their own purposes and the needs of their clients.

The objective of the parent group is to intervene as early as possible in the individual and family dynamics of parents who are faced with the unexpected and challenging task of raising a developmentally disabled child. The thrust of the intervention is to help the parents adjust their expectations about their infant or young child to accomodate his or her handicap, and thereby to prevent the need for institutionalization. This is done by getting the parents to "work through" their own reactions to having a disabled child, to accept that child as a full member of the family, and to begin to focus their energies on coping with the special needs of the child and the rest of the family. It has been my experience that the earlier a family receives appropriate professional services regarding a handicapped child, the more complete this adjustment is.

The group is time-limited and goal-directed. The format was chosen to be structured enough to be replicated and to meet the above-stated objectives within pre-specified time lines, and yet to be flexible enough to accomodate the specific needs of each participant. The topics for each of the meetings were initially suggested by some of the parents in a planning session before the regular group commenced. They were asked to share their biggest concerns about

their handicapped children, and the issues they expressed were grouped into topics for six different meetings.

In summary, this manual is written to guide other group leaders in designing their own parent support group, rather than being a description of what occurred. Consequently, it incorporates what we learned through trial and error into specific step-by-step instructions for implementing a similar group. Other group leaders may find it desirable to alter the procedures somewhat, based on personal preference, client population, and available resources.

INTRODUCTION

Before beginning this kind of group, an important consideration is the qualifications of the leader. It is highly recommended that anyone leading the group meet the following three criteria: First, the person should have received formal training, including hands-on experience, in leading personal growth groups. Second, he or she should also have worked with parents with handicapped children, so as to be familiar with the problems they face. Third, and less tangible, the prospective group leader must be able to relate to the parents in a non-threatening, empathic manner. In other words, the leader's behavior must convey to the parents the message "I understand what you are going through, and I am concerned about you and your family."

One of the first tasks of the group leader is to decide upon the characteristics of those who will be included in the group. First, it's important to involve both mothers and fathers, with few exceptions, in order to foster parental cooperation and consistency in child-rearing. Second, group members should be parents of a child three weeks to four years of age, who has been diagnosed by a physician as either developmentally delayed or developmentally disabled. This age range for the children was chosen in order to focus the group on the initial period of adjustment to the handicapped child. Third, although developmental disabilities encompass both mental retardation and physical handicaps, it is significant that in this group, parents of children with either disability shared very similar concerns. Thus, the group may include parents of children with either type of disability without inhibiting the development of rapport within the group.

The next task is to identify and contact potential group members. Some of the best sources are infant stimulation programs, hospital maternity wards, pediatricians, public schools serving the pre-school age, community mental health

and mental retardation centers, and the local Association for Retarded Citizens. Once a list of potential group members has been obtained, it is suggested that one distribute, in addition to a brief description of the group, a form to be filled out by those who are interested in participating (see Appendix 1). The form provides the group leader with demographic data such as parents' names, addresses, and telephone numbers, and each child's age and type of handicap. Also, it gives a better approximation than does a verbal statement, of how many plan to attend, since returning the form requires some measure of commitment.

Size is another characteristic of the group which must be addressed. It has been my experience that a successful group of this sort requires at least eight individuals (four couples) but no more than twenty. Less than eight is not always dynamic, and more than twenty is too confusing and allows less outspoken persons to remain uninvolved without being noticed. The optimum size group is ten to twelve.

The frequency of the meetings is an important variable, often overlooked in group work. The more frequently the group can be importuned to meet, the more cohesiveness and self-disclosure emerge. If the group meets too infrequently (e.g. once a month) there is little or no carry-over of sentiments from one meeting to the next. It is as if everyone "forgot" whatever rapport previously was developed, and they must repeat at each meeting the early, awkward phase of building trust and solidarity. On the other hand, if the meetings are too frequent (e.g. twice a week), attendance may suffer. Less committed individuals may only want to devote a certain number of evenings per month, and will not attend more frequently. My experiences suggest the group needs to meet at least every other week to maintain a reasonable amount of continuity and cohesiveness; however, weekly meetings would be preferable if the participants express a willingness to make that commitment. It is recommended that

the parents decide the frequency of meetings, with the group leader's guidance. A question to help decide meeting frequency has been included on the form discussed above (Appendix 1).

Two final planning tasks should be completed before scheduling the meetings. These are to invite guest speakers for Meetings #4, #5, and #6, and to reserve audio-visual equipment for Meeting #2. The reason is that the meetings may have to be scheduled around the availability of the guests and equipment.

The group consists of six meetings, each dealing with a different topic, which are presented in a purposeful sequence. Parts of the sequence may be changed if necessary (e.g. due to guests' schedules); however, certain considerations must be kept in mind when scheduling the meetings. The first meeting deals with communication between spouses in hopes the stage will be set from the onset for cooperation and mutual support in future meetings. The session dealing with reactions to the child's handicap (Meeting #3) should not be scheduled any earlier than the third meeting. This is because self-disclosure concerning the emotionally charged issues to be discussed depends on a certain degree of mutual trust and group cohesiveness. These conditions will not likely be present to a large degree in the first few meetings. Finally, since Meeting #6 deals with looking ahead to challenges yet to come, it makes the most sense to schedule it last.

The remainder of this manual consists of specific instructions for each of the meetings. The format for presenting each meeting begins with a brief statement of the objectives for each meeting. This is followed by a list of materials needed. A section called COMMENTS explains the objectives more fully, as well as expanding upon the group process for that meeting. Next, in the section called PLANS, step-by-step instructions are given for implementing the process. In the PLANS sections all passages which are intended to be spoken by the leader at the meetings (e.g. lecturettes and instructions to the group) are indented and set

in quotations to distinguish them from other text. Except for instructions for exercises, it should be noted that it is not intended for the leader to read the manual verbatim. The passages in quotations should be paraphrased by the leader in order to sound more natural.

Finally, there is a post-meeting evaluation form to be completed by the parents after each meeting, and a comprehensive evaluation of the whole group after the last meeting. This serves two purposes. It provides the leader with immediate feedback about the dynamics of each session, which may influence his or her focus in the subsequent session. It also is useful in long range planning for future groups. That is, the feedback may suggest ways to improve the structure of the meeting for the next group of participants.

MEETING #1

"Mothers' and Fathers' Different Expectations and Reactions--How Can we Support Each Other?"

OBJECTIVES

The parents will (1) list and discuss the similarities and differences between the mothers' and fathers' expectations and reactions associated with their developmentally delayed child, and (2) will list some ideas about how mothers and fathers can support one another toward common goals.

MATERIALS

blank paper
pencils
introduction sheets (Appendix 2)
questionnaires (Appendix 3)
post-meeting evaluation forms (Appendix 4)
name tags
blackboard
chalk

COMMENTS

This meeting, being the first, begins with an "ice breaker" exercise to put people at ease and begin to build cohesiveness. Next, as in all six meetings, the leader gives a brief overview to orient the group to the purpose of the meeting. Exercise I gets the members to reflect on their reactions to having a handicapped child, to express those feelings, and as a group to compare mothers' reactions with fathers' reactions. The exercise is primarily intended to build understanding and empathy between spouses by encouraging communication about each others' feelings concerning their child's disability. It can also be helpful to some individuals by getting them to admit feelings they have previously denied.

Exercise 2 builds on the ground covered in Exercise I by moving to specific actions the members could take to support, rather than compete with, their spouses. First, the husbands (or wives may go first) make suggestions as to how their wives could give them more support in dealing with the stresses associated with the handicapped child. The wives are then allowed to ask the husbands questions to clarify their suggestions, but not to make judgmental or opposing comments. It is critical to keep these exchanges on an information-

giving and receiving basis, rather than to allow confrontations to develop. If problems are raised concerning how to implement a suggestion , it is often helpful to ask for input from the group as a whole. Some objective and creative ideas may thus emerge. Next the process is reversed so the wives make suggestions for the husbands. Finally, at the end of the session, an evaluation form (Appendix 4) is distributed and completed by the group members. This is to provide the leader with feedback about the parents' reactions to the meeting.

PLANS

I. Ice Breaker:

Ask everyone to wear a name tag and be seated in a circle. Pass around Introduction Sheets (Appendix 2) and pencils and say:

> *"Rather than just say our names, I have a different way to introduce ourselves and get to know each other. I would like for everyone to find a partner, preferably someone you don't know. Then interview your partners to find out the answers on the Introduction Sheets I am passing around."*

Wait until interviews are completed, then have everyone introduce their partner by telling his or her answers to the interview.

II. Overview (leader says following to group):

> *"The topic of the meeting tonight is called 'Mothers' and Fathers' Different Expectations and Reactions--How Can We Support Each Other?' Having a delayed or handicapped child almost always comes as a surprise and can cause a great deal of stress for both parents. Since mothers and fathers usually have somewhat different roles in the family, they usually feel stress from different things, and often react to it differently as well. Having a handicapped child puts new strain on even the best of marriages. It's a time when parents can either get together and support each other, or can think only about their own problems and work against each other. If they choose to support each other, they are much better able to meet the challenges ahead, and also grow closer to each other. If they don't think about each other's needs and feelings, they may grow further apart and add marital problems on top of the problems posed by the handicapped child."*
>
> *"There are two purposes of this meeting tonight. The first is to explore the similarities and differences between the mothers' and the fathers' expectations and reactions associated with having a developmentally*

delayed child. In other words, let's talk and find out what each other thinks and feels. It's important to communicate with each other. Second, you will have a chance to think of and share some ideas about how mothers and fathers can support each other toward mutual goals for themselves and their child."

III. Exercise 1:

A. Pass out questionnaires (Appendix 3) and give the following instructions:

"Would everyone please think carefully about the questions on this paper and write your answers without showing your spouse, or discussing them. The answers will be shared with the group later."

B. Wait until everyone finishes, then give the following instructions:

"Now I would like each of you to take turns reading your answers aloud. The group should pay close attention to the similarities and differences between what the mothers and fathers say, so you will be able to discuss them afterwards."

Write responses on blackboard in two columns, one for mothers and one for fathers.

C. Discussion: Encourage discussion around the following questions:

(1) *"Are mens' and womens' concerns more or less the same, or different?"*
(2) *"What are the differences on Question #1? The similarities? The differences on Question #2? The similarities? The differences on Question #3? The similarities?"*

IV. Exercise 2:

A. Pass out blank paper and pencils and give the following instructions:

"In the third meeting we will get into a discussion of some of these kinds of emotional reactions everyone has mentioned. But right now I want to move on to exploring ways the husbands and wives can give each other support, instead of working against each other. I would like everyone to write down 3 things your spouse could do to give you support; things which would help you deal with the stresses associated with having a developmentally delayed child. You will be sharing these later, but don't let anyone see your list yet."

B. Ask for a volunteer to go first, and give that person the following instructions:

"Tell your wife some things she could do to give you more support in coping with your delayed child."

Wait until this is done, then say to wife:

"Do you have any <u>questions</u> to ask your husband about what he said? No judgmental comments are allowed--just questions to clarify what he said."

Allow husband to answer questions, then repeat procedure for each individual. Group may give suggestions if someone has questions about how to put a suggestion into practice.

C. Discussion: Open discussion around the following questions:

(1) *"What did you learn from this experience?"*
(2) *"Which ideas for supporting each other had you not thought of yet?"*
(3) *"Which ideas do you think you might put into practice?"*
(4) *"Do you foresee any problems with putting any ideas into practice?"* (If yes:) *"Does anyone have a suggestion or a solution to the problem?"*

V. <u>Evaluation</u>:

Distribute evaluation forms for comments, then collect.

MEETING #2

"Discipline--How Do Our Actions Affect the Development of Our Child?"

OBJECTIVES

The group will learn the basic principles of learning theory (in non-technical terms) and how to apply them to everyday situations encountered in raising a child.

MATERIALS

audio-visual playback equipment (or 16 mm film projector)
two-part videotape by Richard Foxx, et al., entitled Parents and Children: A Positive Approach to Child Management and Behavioral Principles for Parents: A Discrimination Program (or 16 mm film)
handouts covering key terms and principles to be remembered (Appendix 5)
key to solving problem-skits (Appendix 6)
handout of advertisement and order form for Steps to Independence (Appendix 7)
blank paper
pencils
evaluation forms (Appendix 4)

COMMENTS

The basic principles of applied learning theory which are most relevant to child-rearing are listed in a handout (Appendix 5) to be distributed to group members. Part One of the video-tape Parents and Children (also available in 16 mm film) explains these principles in simple, non-technical terms and gives examples by way of dramatization of typical real-life situations. After viewing the videotape and discussing any unclarities, Part Two of the videotape is shown. This segment consists of 31 open-ended skits depicting real-life situations for problem-solving around issues of child-rearing. After each skit, the videotape is stopped and the group is asked what should be done in the situation presented.

After solving about 15 of the skits, the group is to move to a discussion of how the principles can be applied to the particular child-rearing problems of the parents present. In other words, members are encouraged to express their own dilemmas about child-rearing, and discussion centers around how the principles presented earlier might be applicable. The group leader will quickly realize that solving some of the complex problems that members bring up is much more challenging than the cut-and-dry situations depicted in the videotape. An actual

example from one mother comes to mind: You have been trying for weeks to get your child to speak in complete sentences; then during church service she starts babbling away in perfect sentences. Do you reward her for talking in sentences? If so, how? Or do you ignore or punish her for talking in church? And if so, how? Input from other members should be encouraged.

The videotape and/or film can be purchased or rented from Research Press (see Appendix 8 for literature and order form), or the videotape (Betamax size) may be borrowed from this agency.

PLANS

I. Overview:

The leader says the following at the beginning of the meeting:

> *"The topic of the group tonight is 'Discipline--How Do Our Actions Affect the Development of Our Child?' The objectives are for the group to learn some basic principles of learning theory and how to apply them to everyday situations encountered in raising a child. Learning theory is a collection of psychological principles from research findings over the last 50 years which attempts to explain how humans develop their individual habits, attitudes, and personalities. We will avoid technical terms as much as possible and stick to the basics."*
>
> *"I have a two-part videotape to show you. The first part is an introduction to the basic principles of learning theory; and the second part gives a series of short skits--real life situations where these principles could be applied to raising a child. After each skit I will stop the videotape long enough for us to discuss whether the parent acted appropriately or not, and what could have been done differently."*
>
> *"Before we see the tape, I have prepared some handouts to cue you to key terms and principles in part one which must be understood in order to discuss the skits in part two. I also added a couple of points not mentioned in the tape. Take a few minutes to read over the handouts, and hold any questions until after part one of the tape. If you will jot down your questions from the tape and the handout, I will address them all before we go on to part two."*
>
> *"One last point I'd like to make before starting the tape is that no distinction has been made between*

disciplining normal and delayed children. The principles are the same. The only difference is you may see behaviors change faster with normal children since, by definition, they are developing faster."

Pass out blank paper and pencils and wait until everyone finishes reading.

II. Exercise:

A. Part one of videotape: Show part one, then address questions pertaining to the content of the tape and the handout.

B. Part two of videotape, and discussion:

After viewing each skit, stop the tape and ask whether or not the parent acted appropriately, and why. If the parent in the skit acted inappropriately, ask what could have been done differently. Encourage discussion of the rationale for the parents' answers, giving information where necessary.

Follow the above procedure for approximately 15 skits, calling on different individuals to make sure everyone understands the principles being applied.

Refer to Appendix 6 for a key to solving the skits.

Next, open general discussion by saying:

"These are fairly cut-and-dry situations. In real life it is often more difficult to decide what is the best thing to do. (Give example.) Does anyone have an example from their own child-rearing experience where you weren't quite sure what to do? Maybe we could all get something out of discussing it."

Continue with discussion, applying the principles learned to the group's own experiences.

III. Home Training Manuals:

Hand out copies of advertisement and order form for Steps to Independence parent training manuals (Appendix 7). Explain that the manuals provide clear instructions for parents in managing behavior problems, and teaching language and self-help skills to children with special needs; also that various training programs and research studies have found these among the clearest and most effective manuals available for parents. Encourage group to order if they are interested.

IV. Evaluation:

Distribute evaluation forms for comments, then collect.

MEETING #3

"Coping with the Facts--Our Reactions to Our Child's Diagnosis"

OBJECTIVES

The parents will increase their understanding and acceptance of their emotional reactions to their childrens' disabilities by discussing with each other eight psychological phases which parents of disabled children often experience.

MATERIALS

one copy of the book New Directions for Parents of Persons Who Are Mentally Retarded, by Robert Perske
handouts with Perske's eight alternatives for action (Perske, 1973, p. 13)
evaluation forms

COMMENTS

The intention of this meeting is for the parents to talk about the different reactions they have experienced since learning of their childrens' disabilities. Expressing these thoughts and feelings, and hearing about similar experiences from others, will help the parents begin to get a sense that such intense reactions are natural and acceptable. Understanding and acceptance of the reactions as natural is a first step toward facing reality and coping with the situation constructively.

The leader begins the session with an overview explaining the objectives for the meeting and pointing out that painful feelings are a very human way of responding when important expectations are unmet. Next, the parents are asked to silently reflect on all the reactions they have had since learning of their child's disability. This part of the session is a "warmup" to prepare the parents for the upcoming discussion.

In order to facilitate discussion about emotionally charged issues, the leader introduces a book called New Directions for Parents of Persons Who Are Retarded (Perske, 1973). The book describes eight kinds of reactions parents typically experience after learning their child is mentally retarded (the stages apply equally well to parents of physically handicapped children). The leader

reads the description of the various reactions, pausing after each one to ask the group to share any experiences they have had with similar reactions. Finally, the leader winds up the discussion about these reactions with some practical suggestions for coping with them. These alternatives for action, also taken from New Directions, are intended to give parents some concrete directions and ideas about how they can continue to meet the demands of life in spite of the negative reactions they have.

PLANS

I. Overview:

The leader makes the following opening remarks:

> *"The topic of the group tonight is reactions to finding out your child is developmentally delayed or disabled. 'Reactions' means all the emotions and thoughts that you had when you first learned of your child's diagnosis, and since then. Everyone has painful reactions when important expectations are shattered--it's a fact of being human. In this case, most of you probably expected a perfectly healthy baby, and then your expectations were in some way not met. The purpose of this meeting is to talk about your reactions to having those expectations unmet, so you will hopefully understand yourself better and accept your reactions as natural, no matter how painful they may be. Only after you realize it's alright to feel this way at times, and to think those unthinkable thoughts, will you be able to get accustomed to the situation and feel okay again."*

II. Guided Discussion:

The leader continues by giving the following instructions:

> *"The first thing I would like everyone to do is silently think back to the first time you found out something was unusual about your child. What were you thinking at that time?* (Pause for a moment of silent reflection--do not ask for answers.) *How did you feel physically and emotionally?* (Pause.) *Now think back, week by week, since that time. What kinds of feelings have you experienced since then? Have your thoughts changed, if at all?* (Pause.) *How do you feel about the situation now, tonight?"* (Pause.)
>
> *"There is a book called New Directions for Parents of Persons Who Are Retarded, by Robert Perske, which says*

a parent goes through certain psychological phases after the birth of a handicapped child. I'm going to read you some descriptions of these stages and I want you to think about whether or not they sound familiar. See if you can identify with any of this. There is no particular sequence. People jump all around from one stage to the next, and even skip some of them."

"This phase the book calls 'The Glooms':

> *'It's like your spring has run down. You feel so tired you can hardly drag yourself around. The sun may be shining, but it will seem like a cloudy day to you. You may not feel much--on the outside anyway. Food may taste like sawdust, and coffee will be blah. You may not be able to pay complete attention to people who are talking to you. You can feel a lump in your throat--or there will be knots in your stomach. Other nagging pains may occur. Breathing is work, and every once in awhile you may hear yourself sighing. You may wonder if you have the flu. You may catch yourself talking to yourself. Somehow, through all this, you wish you could find a warm cozy hole, crawl into it, and pull the lid after you.' (Perske, 1973, p. 10)*

After reading aloud the above description of "The Glooms", the leader encourages group members to share their own past experiences, memories of which the description evoked. He or she may wish to give the clinical name for "The Glooms", i.e. depression. Questions such as the following may help stimulate discussion:

"Has anyone ever felt like this?" "Could you tell us what it was like?"
"Does food really lose it's taste?"
"Is it hard to listen to people?"
"What do you do when you feel that way?" "What <u>can</u> you do?"

The leader may point out, as the author of <u>New Directions</u> does, that when you feel this way it's okay to slow down, take some time out, and "climb into your shell"--but don't stay too long. Sooner or later you must pick yourself up and do the things you have to do.

After sufficient discussion about "The Glooms", move on to the next stage:

"Another stage is called 'The Speeds':

'When this stage approaches, it's like somebody wound your spring too tight. You may move around like a high-speed mechanical vaccum sweeper:

so much to do.
so much ground to cover.
so many places to go.
so many people to see.
so many things to say.

When this hits, your mind and body perceive there are lots of new things you must receive and digest. It's your personality's way of 'getting at it' even if there are a lot of wasted motions.' (Perske, 1973, p. 11)

"Another name for this is 'Newness Panic' because it's a common reaction in any kind of new situation. You don't know what to expect, and you react with a lot of frantic activity, often without getting anything constructive accomplished."

Again, encourage discussion with questions such as the following:

"Has anyone been through 'The Speeds?' Tell us what it was like."
"What can you do when 'The Speeds' hit?"

"Another stage is called 'The Blocks':

'You have been shown the signs of your child's delay and the doctor has spoken to you about it, but your eyes don't want to see it and your ears refuse to hear it. You still want to believe that your child is superbaby. It is hard to believe that your child will have a rate of growth coded into himself that is not what you had hopefully planned. You may even talk as if he's not the way he is. That's O.K. for a time. Every parent's mind must have time to lower its sights from having superbaby to seeing the child as he or she really is.' (Perske, 1973, p. 12)

Use questions such as the following to stimulate discussion:

"Have any of you found yourself refusing to believe the facts about your child's delay, only to realize later that you could no longer deny them? ... (Wait for a response) *... Would you be willing to share some of these blocks with us?"*

The leader should keep in mind that some denial is healthy. Doctors may give conservative estimates of a child's potential so as not to have the parents let down due to too high expectactions. In such cases, the parents would not be doing justice to the child to accept for him the limitations implicit in the doctor's diagnosis.

After hearing several "testimonials" and subsequent discussion about "The Blocks", summarize this stage as follows:

"Every parent must make this shift from thinking about the perfect baby they hoped for, to accepting their child with its strenghts and weaknesses. But with a delayed baby the shift is especially abrupt and hard to make. Another name for 'The Blocks' is denial. It's normal to deny something that you can't adjust to immediately. You can't help it. But it's a bad thing if your mind never makes the shift to accepting the facts."

"Are there any more questions or comments about this stage before we move on?"

"Another stage is called 'The Hurts':

> *'How can one explain all the types of anguish and pain felt by parents of children who are developmentally disabled. There are so many forms of it. Put all of these mental and physical anguishes together and one is forced to admit that it not only hurts; it hurts bad! The hurts may force you to become edgy and nervous. At times you may break down and cry. You may lie awake all night, tossing and turning. You may walk the floors. All this frenzied action is as if you are agitated and moving about in order to do something to stop the pain.' (Perske, 1973, p. 12)*

Use comments and questions such as the following to stimulate discussion:

"This is similar to 'The Glooms' except that instead of being depressed about the situation you are agitated and nervous. Can anyone identify with periods of 'The Hurts'?"

After sufficient discussion, summarize this stage with the following words:

"The author makes an important point to keep in mind when you feel a strong case of 'The Hurts': 'You will never really suffer pain beyond what you can endure. The body and mind have many mechanisms to slow down and dull the senses before things get to an overwhelming state. Also, people become stronger when they endure pain'; (Perske, 1973, p. 12) that is, if they don't run away from the problem."

"Are there any more comments about this stage before we move on?"

"Another stage is called 'The Guilts':

> *'There will be times when your mind tells you that you must have committed some horrible sin against God and man. Do you feel the need to look back into your past and search for that "horrid thing" that has caused it all. I'm willing to wager that no matter how hard you look, you probably won't find it. And whatever it was that caused your son or daughter to be disabled will largely remain a mystery that you must accept.'*
>
> *'Nevertheless, on some days you will feel sure that you are the worst specimen of humanity in all the world. Somewhere, somehow, you have committed an unpardonable sin, and now you are paying for it. Such guilt as this is phony. It's not the same kind of guilt you feel when you are caught with*

your hand in the cookie jar. That's real guilt with real evidence. This is different. You feel deeply guilty, but there is no evidence to justify the guilt no matter how hard you try to drag out the black things in your life and say, 'That must be the reason'." (Perske, 1973, p. 12)

Use questions such as the following to stimulate discussion:

"Has anyone experienced feelings of guilt over the condition of your child, which you would be willing to share with us?"

After eliciting discussion of several people's experience, ask: "What does Perske mean when he says "such guilt is phony?" The point which should surface is that the parents could not be at fault; rather, this is just another psychological reaction caused by having important expectations unmet.

"Another stage is called 'The Greats':

'Where a few days earlier you may have felt that you were the world's worst, now it may come to you that you are one of the greatest. You feel that maybe God has chosen you to bear this extra burden because you are secretly greater, holier, and more special than the rest of the human beings around you. You are a martyr. It is much more pleasant to fantasize yourself as being great. It's much better than feeling you are the world's worst mom or dad.' (Perske, 1973, p. 12)

Stimulate discussion by asking:

"Has anyone ever experienced 'The Greats'? What was that like?"

After sufficient discussion, paraphrase Perske's advice as follows:

"This stage is rather pleasant, so enjoy it while you can. But sooner or later somebody will say something, or something will happen, to send you crashing down off your pedestal. Hopefully, as these crashes come you don't fall into the guilt trap again. Instead, you may begin to realize you aren't a superparent but you aren't the worst parent either. You have your strengths and weaknesses like everyone else."

"Another stage is called 'The Hates':

'After you've hurt for a time, you may irrationally search for chances to blame others and hurt them. Almost anybody you think of could become the target:

your spouse
your neighbor
your doctor
your minister
your children

So, you watch and wait. All those around you--being human--will sooner or later say or do some little thing that will give you "justification" and then you can really unleash your anger at them for a time.' (Perske, 1973, p. 12-13)

Again, encourage members to discuss past experiences with 'The Hates', then summarize with the following observations taken from New Directions:

"It's all right to feel such anger and hatred, even though it's irrational. But acting on that anger can be precarious, because you do things which may give you another dose of the guilts afterwards, and the vicious circle starts all over again."

"The final state in the book is called 'The Give-Ups':

'There may be some times when you will wake up at 2:00 a.m., wish you could close your eyes and never open them again. We usually keep these thoughts secret, because we're ashamed of them. But many parents of children who are disabled openly confess to stages when they felt the give-ups.'

'This usually happens when the problems of your child's disability loom unrealistically big. You forget the other sweet and sour ingredients that make living a genuinely good thing. At this moment your mind sees only this one painful trauma blown up way out of proportion. You feel helpless to do anything, and all you want to do is escape.' (Perske, 1973, p. 13)

Encourage discussion of personal experiences of the members concerning this stage.

After the discussion, pass around copies of Perske's eight alternatives for action, listed below. Then end the meeting with a discussion of alternatives for action, beginning with the following remarks:

"All these stages overlap and get mixed up, but one thing is obvious: You go through some very intense reactions the first year. Later they merely become history, and you will have to rack your brain about how you really felt. But considering the difficulties of the first year, here are some practical suggestions from Perske's book: (Read aloud while others read their copy silently.)

1. *Do not threaten to end it all. Sooner or later you will find that is a stupid thing to do. It creates more problems than it solves.*

2. *Don't divorce your mate this week. Later on it may not matter that you feel he or she has let you down. Better learn how to work as a team.*

3. *Do not blame your doctor. The news that your child is retarded will hurt no matter how he tells you. Also, the doctor, hating his own human weakness, may be stricken with a dose of "the greats" before your very eyes. If that continues to happen, you may need to find a doctor who can be humanly honest with you.*

4. *If you find yourself in the glooms, enjoy the misery only for a limited time. Then get up. Move those muscles. Work. Scrub that sink or mow that lawn. Do it, even though you don't want to.*

5. *If the speeds get you, stop. Then talk slow, walk slow. Pick only one of the 241,000 things you feel you should do for that day and do it.*

6. *Learn to admit to yourself that no matter how real these feelings may seem, they are weird and unreal. They will pass.*

7. *Learn that time is your best friend. In time, the most beautiful sanity can come out of the roughest chaos.*

8. *You have a precious opportunity to learn what it means to be strong and tender at the same time--with yourself, your child, and those around you.*

(Perske, 1973, p. 13)

Stimulate discussion about alternatives for action by asking if anyone has any questions or comments about these suggestions by Robert Perske.

III. Evaluation:

Distribute evaluation forms for comments, then collect.

MEETING #4

"Setting Goals for Our Children--What is Realistic?"

OBJECTIVES

The parents will become aware of the pitfalls of expecting either too much or too little of their children, in terms of their development, by discussing the subject with a developmental pediatrician.

MATERIALS

evaluation forms

COMMENTS

The purpose of this session is to help the parents develop realistic expectations concerning their childrens' potential for development as individuals. Parents of the disabled must steer a course between demanding more than their children can deliver, which impedes development of positive self-concept, on one hand, and overprotecting them, which prevents development of their full potential, on the other hand. This cannot be learned in one evening, of course, but the ground-work can be done by getting the parents to look at the task of child-rearing in terms of avoiding these two extremes.

The assistance of a developmental pediatrician is needed for this session. Ideally, this person whom the group leader invites as a guest for the evening, must be experienced with handicapped children and their families, and must have an empathic, non-threatening interpersonal style of delivery. The guest for the present group was a Navy pediatrician located through the Naval Regional Medical Center in Portsmouth, Virginia. Other possible sources for a guest speaker are hospitals and clinics serving infants and children, especially those who frequently refer families to the agency conducting the parents' group.

The meeting begins with the guest talking for 15-30 minutes on the subject of setting realistic goals for a disabled child. Next, the parents are invited to ask questions, and group discussion is encouraged. The prospect of free medical advice is likely to generate a great deal of interest and discussion.

The expertise of a pediatrician is essential for some of the specific questions about child development which are likely to emerge. The group leader's responsibilities are to guide the group within the scope of the outlined objectives, and make sure everyone who wants to has a chance to talk. The success of the session depends largely on the skills of the pediatrician and how well the group leader clarifies the objectives for him or her in advance.

PLANS

I. Preparation (before meeting):

Invite a developmental pediatrician one to two months in advance to speak to the group on the topic of setting goals for a handicapped child, and to answer subsequent questions concerning child development. It is important that the group leader clarify for the guest the purpose of the group as a whole, as well as the specific objectives for this session. The parents should be informed in advance (i.e. at Meeting #3) that a physician will be in attendance, and encouraged to bring in questions concerning goal-setting for their child.

II. Procedures (during meeting):

A. Overview:

Leader begins the session with the following remarks:

> *"The topic of our meeting tonight is setting realistic goals for our children. It has been my experience working with families with handicapped children that parents often go to either of two extremes with their children. The first is, they want their children to develop so fast that they push them beyond their capacity, which is very frustrating for a child. When you are always falling short of someone's expectations you begin to feel that you are a bumbling failure. The other extreme is to over-protect children so that they never have the opportunity to develop their full potential. These parents seem to think 'since Johnny is retarded, or has cerebral palsy, he needs to be protected from the cold, cruel world.' But you can't protect children 24 hours a day for the rest of their lives. Sooner or later they are going to have to face the real world, and if they have been guarded all their lives they are not going to know what to do when that day comes. What I hope you will gain from the meeting tonight is an awareness of the importance of steering a course between these two extremes. To begin the meeting, Dr. _____ is going to speak to you for a few minutes about setting goals for your children. Then we will open the floor for questions and discussion."*

B. Introduce the guest, who is then to speak to the group for 15-30 minutes about setting goals for a handicapped child.

C. After the guest has spoken, open discussion by inviting parents to direct any questions to him or her. The mood and number of questions from the group will determine the length of the meeting.

III. Evaluation:

Distribute evaluation forms for comments, then collect.

MEETING #5

"What About the Rest of the Family--How are They Affected?"

OBJECTIVES

The parents will increase their awareness of the ways a handicapped child impacts on the rest of the family by discussing the subject with five adolescents who have handicapped siblings. As a result of this discussion the parents will be more able to minimize the negative impact of the child on the rest of the family, and will be more likely to take a problem-solving approach to problems than to react impulsively.

MATERIALS

list of questions for discussion (see Procedures below)
evaluation forms

COMMENTS

The purpose of this session is to increase the parents' awareness about the effects a handicapped child has on the other members of the family--other siblings in particular. As a result of this awareness, the parents will be more sensitive to such potential problems as sibling competition for parental attention, one sibling's resentment over having to take care of another, and the non-disabled sibling's feelings about his peers meeting the disabled sibling. First, the parents will be more likely to minimize such problems by preventive action; for example, being careful to spend time with each of their children. Second, when problems do arise, if parents anticipate the problems they will be more likely to take a problem-solving approach than to react impulsively and destructively.

In order to make the parents more aware of the ways a disabled child impacts on his or her siblings, one of the most stimulating and convincing approaches is to invite a "guest panel" of five adolescents who have handicapped siblings to speak with the group. A guest panel may be identified by contacting the families of developmentally disabled children on the caseload of the agency sponsoring the group. The ideal ages of the guests are between 15 and 18 years. Persons in this age group are likely to be mature enough to participate in a group discussion, and yet young enough for the experience of growing up with the handicapped

sibling to be fresh in their minds. The nature of the guests' siblings' handicaps should be as representative as possible of the parents' own childrens' handicaps.

The group process begins with the leader stating the purpose of the meeting. Next, the guests are asked to introduce themselves and tell a little about their handicapped siblings. The remainder of the meeting consists of a group discussion. The group leader's responsibilities during the meeting are to guide the discussion, being sure to cover the topics listed below in Procedures, and to encourage everyone's participation. This will require an active role the first 10 to 20 minutes, asking questions to stimulate discussion. However, the group will likely carry the discussion on its own after awhile, and only occasional interventions will be required of the leader.

PLANS

I. Preparation (before meeting):

Invite five individuals who have developmentally disabled siblings to attend a group discussion on their experiences growing up with those siblings. The guests should be informed three weeks in advance of the purpose and format of the meeting. They should be told that if they agree to participate they will be asked at the opening of the meeting to introduce themselves and tell a little about their handicapped sibling (e.g. his or her age, nature of handicap, and daily routine). Further, they will be expected to answer questions and participate in a discussion about their own experiences growing up with a handicapped sibling. The guests should receive a list of questions they can expect to be asked.

II. Procedures (during meeting):

A. Overview:

The leader begins the session with the following remarks:

> *"The purpose of the meeting tonight is to find out how a handicapped child affects the rest of his or her family--the brothers and sisters especially. If you are aware of some of the potential problems, you will likely be better able to minimize the negative effects. What I hope you will gain from the meeting tonight is an awareness of both the positive and negative ways a handicapped child can effect his or her siblings. Furthermore, I hope this awareness will prepare you to take a constructive, problem-solving approach when the negative issues arise, rather than feeling helpless to do anything."*

"Instead of you or me speculating about how a handicapped child affects his or her siblings I think the best way to learn about this is to hear it from someone who has a handicapped brother or sister. I've invited five guests tonight to be part of a discussion concerning what it's like growing up with a handicapped brother or sister. After the guests introduce themselves and tell us a little bit about their siblings, feel free to ask them questions and join the discussion."

Ask each of the guests to take a few minutes to introduce themselves and tell the group about their handicapped sibling. It is important at this point to probe for details about each handicapped child (e.g. ages, nature of handicap, strengths and weaknesses, residential and vocational activities), so the group has some familiarity with the individuals who will be the focus of the discussion. Next, open general discussion by asking the group if they have any questions or comments for the guests. Discussion can be stimulated as necessary by asking questions, a list of which is provided below.

Questions for guests:

"What kinds of problems or extra responsibilities did having a handicapped brother/sister involve for you?"

"How did you feel when your friends met your brother/sister?" "How did you explain his or her disability?"

"Did you have to babysit or care for your sibling often?" "How did you feel about that?"

"Did you ever feel your brother/sister was getting preferential treatment from your parents?" "What was it like?"

"How did your relatives respond to the handicapped child?" "Were they helpful or not?"

"What do you wish your parents had done differently?"

"What were the positive aspects to growing up with a handicapped sibling?" "What did you gain from the experience?" (This question should be saved until last so as to end with a positive tone.)

Questions for parents:

"How did you react to what was said?"

"What was surprising or unexpected to you?"

"What did you learn that could help you in raising your own family?"

III. Evaluation

Distribute evaluation forms for comments, then collect.

MEETING #6

"What Lies Ahead for Us?"

OBJECTIVES

The parents will increase their awareness of the kinds of challenges they are likely to encounter throughout the lifetime of their handicapped child by discussing the subject with other parents who have raised handicapped children. As a result, the parents will be more able to face these challenges constructively as they arise, rather than being emotionally overwhelmed by one crisis after another.

MATERIALS

list of questions for discussion (see Procedures below)
evaluation forms
handouts with names, addresses, and phone numbers of all group members

COMMENTS

The focus of this meeting is on the entire developmental period of the handicapped child. The parents will discuss with other parents who have raised a handicapped child such potential problems as the child's school experiences, the reactions of non-handicapped peers the child encounters growing up, the child's sexuality, decisions about institutionalization, and the child's desire for increasing independence as he or she gets older. By discussing these issues before they arise, the parents will be more able to cope with the issues constructively when they do arise. The parents will become somewhat emotionally prepared because the problems will be expected.

The approach to this session is similar to that in Meeting #5. A guest panel of four couples who have handicapped sons or daughters are invited to talk to the parents. Prospective individuals for the panel can be identified from the caseload of the agency sponsoring the group. The guests should be chosen on the basis of good adjustment to the task of raising a handicapped child, since they will serve as models for the parents in the group. They should also be people who find it easy to disclose personal experiences to a group of strangers. Finally, their children's ages should range from early

teens to mid-twenties to get a good cross-section, and their handicaps should be as representative as possible of the parents' own childrens' handicaps.

As in Meeting #5, the group process begins with the leader stating the purpose of the meeting, and then asking the guests to introduce themselves and tell a little about their handicapped children. The remainder of the meeting consists of a group discussion, and again, the leader's role is to guide the discussion and encourage everyone's participation. The questions in the Procedures section, which the leader asks the guests and the group members, serve to stimulate discussion when there is a lull, and to ensure that these important issues are not overlooked. It is suggested that the question *"What were the most positive aspects of raising a handicapped child?"* be asked last in order to end with a positive tone and leave the parents feeling somewhat optimistic.

At the end of the meeting the leader distributes a list of all members' names, addresses, and telephone numbers. This is to encourage continued contact between group members for mutual support and friendship. It is important for parents to have friends they feel understand what they are going through. Friendships begun in the group's atmosphere of trust and self-disclosure may last for years given a chance, and having a list of phone numbers facilitates that process.

PLANS

I. Preparation (before meeting):

Invite four couples who have a handicapped child between 12 and 25 years of age, a month in advance, to attend a discussion about their experiences raising that child. Inform the guests of the purpose and format of the meeting. They should be told that if they agree to particiapte they will be asked at the opening of the meeting to introduce themselves and tell a little about their handicapped child. Next they will be expected to participate in a discussion about their experiences raising that child. The guests should receive a list of questions they can expect to be asked (see Procedures below).

II. Procedures (during meeting):

A. Overview:

The leader opens the session with the following remarks:

> *"Tonight is the last meeting of this group. The purpose of this meeting is for you to become aware of some of the challenges you are likely to face in the future, in terms of raising a developmentally disabled child. The focus is the entire developmental period of your child--probably through the early twenties or even later. We have some guests tonight who have older handicapped children than you and therefore have some experiences that should be informative to you. They are going to talk to us about some of the challenges they faced raising their children, challenges which you will probably also face. What I hope you will gain from this discussion is an awareness of some of these potential problems that lie ahead, because when you anticipate problems it's usually easier to cope with them, instead of being emotionally overwhelmed. Also, I hope you will realize some of the very positive things your child can bring into your life."*

B. Ask each of the guests to take a few minutes to introduce themselves and tell the group about their handicapped child. It is important at this point to probe for details about each handicapped child (e.g. ages, nature of handicap, strengths and weaknesses, residential and vocational activities), so the group has some familiarity with the individuals who will be the focus of the discussion. Next, begin the general discussion by asking the group if they have any comments or questions for the guests. Discussion can be catalyzed as necessary by comments and questions such as the following:

Directed toward guests:

> *"Some parents describe the task of raising a handicapped child as characterized by challenges (or crises) occurring at different stages, and after you have met each new challenge there is a period of calm with everything going fairly smoothly until the next challenge comes along. Would you agree with this description?" "Why, or why not?"*
>
> *"What were some of the critical challenges you faced?" "How did you react to each one?"*
>
> *"How did you react to the following experiences, if relevant:*
> - *the way people react in public if your child appears 'different'.*
> - *the child's entrance into school and subsequent academic performance.*
> - *reaction of non-handicapped peers.*
> - *the child's puberty and sexuality.*
> - *his or her desire for independence and age-appropriate activities (especially in adolescence and adulthood).*
> - *job training and employment.*

- the decision about whether or not to place your child in a residence away from home.
- problems securing services for your child.
- medical problems."

"What were the most positive things about raising this child?"

Directed toward parents in group:

"How did you react to what was said?"

"What was surprising or unexpected to you?"

"What did you learn that could help you in raising your own child?"

C. Distribute lists of members' names, addresses and telephone numbers, and encourage group to stay in contact with one another for mutual support and "friends who understand."

III. Final Evaluation:

Pass around final evaluation form (Appendix 9) and ask everyone to complete it as carefully as possible to help with planning future groups of this nature.

APPENDIX 1

INFORMATION FOR GROUP PLANNING

NAME: _____

ADDRESS: _____

_____

PHONE NUMBER: _____

YOUR CHILD'S NAME: _____ CHILD'S AGE: _____

DESCRIBE YOUR CHILD'S HANDICAP OR DELAY:

_____

_____

HOW FREQUENTLY WOULD YOU BE WILLING TO MEET? (CHECK ALL THAT APPLY):

_____ TWICE A WEEK

_____ ONCE A WEEK

_____ EVERY OTHER WEEK

_____ EVERY THIRD WEEK

_____ ONCE A MONTH

FILL IN WHAT HOURS YOU WOULD BE AVAILABLE TO MEET:

MON. _____ TUES. _____ WED. _____ THURS. _____ FRI. _____

APPENDIX 2

INTRODUCTION SHEET FOR MEETING #1

Instructions: Choose a partner whom you don't know. Interview each other to obtain each other's responses to the following incomplete statements. When all interviews are completed, everyone will take turns introducing their partners to the group.

He/she is the kind of person who likes:

1.

2.

3.

He/she greatly appreciates and values:

1.

2.

3.

Some of his/her dislikes or pet peeves are:

1.

2.

3.

Someday he/she would like to:

1.

2.

3.

APPENDIX 3

QUESTIONNAIRE FOR MEETING #1

Instructions: Carefully think about and answer the following questions. Please do not share your answers with anyone until we do so as a group.

1. Right now my 3 major concerns related to my developmentally delayed child are:

   (a) _____

   (b) _____

   (c) _____

2. Three emotions that best describe my reactions to my child's problems are:

   (a) _____

   (b) _____

   (c) _____

3. Since finding out about my child's developmental delay, I have personally changed in the following ways:

   (a) _____

   (b) _____

   (c) _____

APPENDIX 4

POST-MEETING EVALUATION FORM FOR MEETINGS #1 - #5

Instructions: Please answer the following as completely and honestly as possible in order to help plan future groups.

1. Please list and explain your opinion of what went well and what went poorly tonight.

   A. Well . . .

   B. Poorly . . .

2. What suggestions or other comments do you have which might help us in planning future groups of this type?

APPENDIX 5

KEY TERMS AND PRINCIPLES IN LEARNING THEORY*

1. Consequences: The primary way you can help your child learn to live a happy, well-adjusted life is to teach him or her that there are good consequences for appropriate behaviors, and bad consequences for inappropriate behaviors. Consequences can be either rewards, punishments, or nothing (ignoring).

2. Rewards: Behaviors which are followed by rewards tend to increase in frequency. Remember the following principles concerning the delivery of rewards:

   a. immediacy - the reward must follow the behavior immediately to have maximum effect.

   b. intermittent rewards - it is sufficient to reward on an intermittent basis those behaviors which it is not practical to reward constantly.

   c. ask children what they like - this is a good way to choose what reward to use (usually time with you in a favorite activity is the greatest reward.)

   d. Grandma's Rule - use an activity children like as a reward for doing a task they do not like.

   e. control your own emotions - you cannot shape good behavior by anger or yelling; you must shape it gradually, over the course of time, with rewards.

3. Punishment: Physical punishment (e.g. spanking) should be avoided as much as possible because it has certain negative side effects, even though it seems to work to decrease behavior in the short run. These side effects are:

   a. the child learns to dislike and avoid both the person dispensing punishment and the kinds of situations in which punishment is dispensed (e.g. family outings).

   b. excessive use of punishment over time tends to produce an individual who is authoritarian, conforming, and dependent, as opposed to one who is sensitive, creative, and enterprising.

   Time-out and logical consequences can be used for inappropriate behaviors, in place of physical punishment, to avoid the above problems.

   Time-out means removal from rewarding situations for a specified length of time. For example, having a child stand in the corner or go to his room (absent any toys!).

   Logical consequences can be punishing in the sense of being unpleasant, but the advantage is they follow logically from the misbehavior and are therefore seen by the child as incurred by himself, not inflicted by you. An example of a logical consequence is when a child breaks a window and you make him work to earn money to replace it.

4. Ignoring inappropriate behavior: Many bad behaviors (tantrums are a prime example) will disappear simply by ignoring them. This is because in the absence of your attention the behaviors are no longer being rewarded. This technique, too, is preferrable to punishment.

   Important: You must be resolved to control yourself and wait the child out when ignoring inappropriate behavior, as it usually gets worse before it gets better.

5. Structuring a task: Often a child fails to do what you ask simply because she or he doesn't know how or doesn't comprehend exactly what you are requesting. You can often avoid this situation by using the following techniques when instructing a child about something to do:

   a. break the task down into small steps, presented in a logical sequence, from beginning to end.

   b. provide verbal cues and/or physical assistance as needed.

   c. provide verbal assurance and praise after each step or several steps.

*This information is taken largely from the film Parents and Children (Foxx, et al.).

APPENDIX 6

KEY TO PROBLEM SKITS IN PART TWO OF PARENTS AND CHILDREN

Frame No.	Solutions
1.	Wrong: good behavior was followed with punishing consequences.
2.	Wrong: good behavior was ignored.
3.	Right: good behavior was followed with reward.
4.	Wrong: bad behavior was rewarded.
5.	Right: bad behavior was ignored.
6.	Wrong: a difficult task was given without breaking it down into steps.
7.	Right: a difficult task was broken down into small, clear components.
8.	Wrong: bad behavior was rewarded.
9.	Right: good behavior was rewarded.
10.	Wrong: good behavior was ignored.
11.	Right: employed Grandma's Rule by using a preferred activity as reward for a nonpreferred activity.
12.	Wrong: good behavior was ignored.
13.	Wrong: was given a difficult list of tasks without breaking them down or giving cues or assistance.
14.	Right: difficult task was broken down into components.
15.	Wrong: good behavior was ignored.
16.	Right: bad behavior was ignored, then subsequent good behavior was rewarded.
17.	Wrong: good behavior was not followed immediately by reward.
18.	Right: good behavior was rewarded.
19.	Wrong: bad behavior was rewarded.
20.	Right: good behavior was rewarded.
21.	Wrong: bad behavior was rewarded.
22.	Wrong: good behavior was punished.

Frame No.	Solutions
23.	Fill-in-blank type: one could use Grandma's Rule and have him clear the table first, then watch T.V.
24.	Fill-in-blank type: one should break the task down into simpler components.
25.	Right: a difficult task was broken down and rewards given at each step.
26.	Right: used Grandma's Rule as in Frame 11.
27.	Wrong: parent distracted child with a reward before he did the task, instead of after.
28.	Wrong: good behavior was punished.
29.	Wrong: bad behavior was rewarded--parent should have made child clean up ice cream first, then rewarded him for cleaning up.
30.	Right: good behavior rewarded.
31.	Wrong: good behavior ignored (i.e. child helped by picking up clothes).

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among a greater range of people, places, and things • follow more complex directions • understand such concepts as yes and no, size, colors, and speed • imitate more difficult mouth movements and sounds • increase vocabulary and • speak more clearly.

Both manuals are oriented toward brief daily structured teaching sessions. They also stress the opportunities throughout the day for incidental teaching. Each book includes a speech and language assessment scale to evaluate the child's current skills.

Speech and Language: Level 1, spiralbound, 8½ x 11, 82 pages
Item No. 1816 1-9 copies **$7.95 each**
10+ copies 7.15 each

Speech and Language: Level 2, spiralbound, 8½ x 11, 106 pages
Item No. 1824 1-9 copies **$7.95 each**
10+ copies 7.15 each

The instructional guidelines are clear, concise, and easy for parents to understand. Many examples are provided along with appealing cartoons which illustrate specific points. The activities suggested are varied and suited to whole family participation which is encouraged by the authors.

Toni Linder, *Journal for Special Educators*

Behavior Problems

Anyone interested in managing children's behavior will appreciate this excellent manual. *Behavior Problems* stresses • specifying the problem behavior • measuring its occurrence • identifying the antecedents and consequences and then • developing a program to reduce and discourage the problem behavior while increasing and encouraging desired behaviors. The focus is on problem behaviors characteristic of children with special needs, such as self-stimulation, self-abuse, and fearful behaviors.

Behavior Problems, spiralbound, 8½ x 11, 120 pages
Item No. 1700 1-9 copies **$7.95 each**
10+ copies 7.15 each

NEW in '80 **October**

Toward Independent Living

This new manual presents strategies and step-by-step instructions for teaching independent living skills to retarded children, adolescents, and adults. Part One focuses on the daily self-care skills — • dressing • grooming and • health care — necessary to make a good appearance in public. It also offers training in the home care skills that are required to keep a home running smoothly. Part Two focuses on skills necessary for independent living in the community. These skills include • recognizing protection words • using a telephone • telling time and • handling money. Teaching strategies include rewarding, prompting, fading prompts, modeling, and implementing token systems.

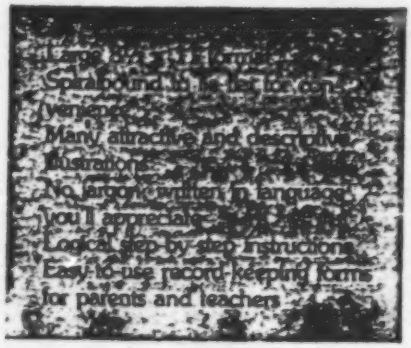
For more information about this new manual, refer to page 5.

Toward Independent Living, spiralbound, 8½ x 11, approximately 112 pages
Item No. 2219 1-9 copies **$7.95 each**
10+ copies 7.15 each

Training Guide

Features a behavioral assessment guide which permits parents and teachers to determine the appropriate manual for each child. For use by counselors working with parents and teachers.

Training Guide, papercover, 8½ x 11, 28 pages
Item No. 1719 **$2.95 each**



Written with the assistance of parents, this series of books presents a realistic approach to the use of behavior modification. Recognizing that most self-help skills are taught naturally in the home, each step that goes into acquiring a specific skill is carefully explained for parents.

Ruth Fitzgerald, *Advocate*

a readable, nontechnical, step-by-step format that is encouraging to the unsophisticated reader who is looking for answers on how to train children with special needs

Marianne L. Punchard, *The American Journal of Occupational Therapy*

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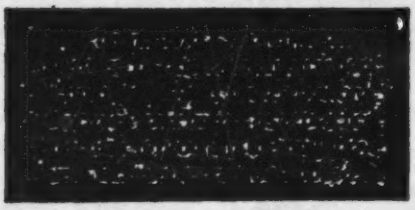
APPENDIX 8

INFORMATION FOR ORDERING PARENTS AND CHILDREN AND BEHAVIORAL PRINCIPLES FOR PARENTS*

Outstanding Films for Successful Parent Training



Parents and Children

A Positive Approach to Child Management

Featuring Dr. Richard M. Foxx
Content Consultants, Dr. Rex Forehand and Dr. Richard M. Foxx
Produced by Norman E. Baxley and Dr. Gladys B. Baxley with Research Press

The first major film to deal exclusively with teaching children through the proper use of behavioral methods, *Parents and Children* presents an overview of reinforcement principles in easily understood, nontechnical language. It is narrated by Dr. Richard M. Foxx, a recognized expert in the use of behavioral techniques. Parents can identify easily with the realistic, everyday examples that appear throughout the film.

Parents and Children examines the parent-child relationship as a special learning experience in which the purposeful use of rewards can play a crucial role. It also demonstrates the proper use of time out and of ignoring inappropriate behavior. Concepts presented in this film include • the learning experience between parent and child • how and when to use rewards effectively • attention, activity, and material rewards • strengthening or maintaining good behavior • teaching new or complex behavior and • eliminating undesirable behavior.

Parents and Children offers a positive approach to parents who are interested in motivating and teaching their children. It is an excellent aid to teachers, psychologists, social workers, and other professionals involved in parent training.

expertly handled, blending judicious amounts of narration with everyday real-life situations
Joseph F. Kosloski,
Luzerne County Community College

16mm film or ¾" videocassette, color, 24 minutes

Film Purchase
Item No. 1958 **$395.00**

Film Rental
Item No. 1959 **$45/3 days**

Videocassette Purchase
Item No. 1960 **$395.00**

Behavioral Principles for Parents

A Discrimination Program

Content Consultant, Dr. Rex Forehand
Produced by Norman E. Baxley

This unique training program consists of 31 short vignettes of parent-child interactions. These include examples of positive reinforcement of both appropriate and inappropriate behaviors, punishment of both appropriate and inappropriate behaviors, time-out procedures, and extinction. The importance of giving simple, clearly stated instructions is also demonstrated.

Parents will develop an understanding of behavioral principles during the discussion time provided after each scene. Some vignettes show incomplete interactions, and viewers are encouraged to form their own responses in order to complete each interaction.

Behavioral Principles for Parents is easy to use and does not require extensive preparation. The *Leader's Guide* contains the script and discussion questions for each scene. Trainers and group leaders will welcome this film as an adjunct to any parent training program.

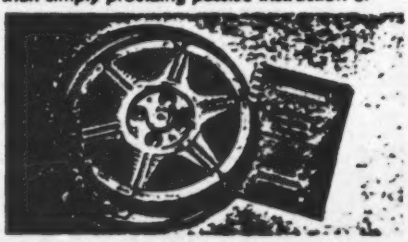
This is an unusual film because it encourages instructional interaction among viewers rather than simply providing passive instruction or entertainment . . . Behavioral Principles for Parents is not simply a reference guide; it is an excellent instructional tool.
David Nolley, *AAAS Science Books and Films*

16mm film or ¾" videocassette, color, 13 minutes, includes *Leader's Guide*

Film Purchase
Item No. 1961 **$210.00**

Film Rental
Item No. 1962 **$35/3 days**

Videocassette Purchase
Item No. 1963 **$210.00**



* USE SAME ORDER FORM AS IN APPENDIX 7.

APPENDIX 9

FINAL EVALUATION FORM

Please take your time to answer this evaluation as fully and honestly as possible. The information will be used to plan future parent groups.

Thank you.

1. Check which meetings you attended, as best you remember:

_____ Meeting 1: "Mothers' and Fathers' Different Expectations and Reactions--How Can We Support Each Other" (structured discussion).

_____ Meeting 2: "Discipline--How Do Our Actions Affect the Development of Our Child?" (videotape and discussion).

_____ Meeting 3: "Coping With The Facts--Our Reactions to Our Child's Diagnosis" (structured discussion).

_____ Meeting 4: "Goals For Our Children--What is Realistic?" (Dr. _____, Pediatrician, was guest).

_____ Meeting 5: "What About The Rest Of The Family--How Are They Affected?" (discussion with guest sibling panel).

_____ Meeting 6: "What Lies Ahead For Us?" (discussion with guest panel of parents).

2. Which meetings did you like the best?

_____

Explain your reasons: _____

_____

_____

3. Which meetings did you like the least?

_____

Explain your reasons: _____

_____

_____

4. Specifically, what topics or issues would you like to have covered in more detail?

5. Which group formats did you gain the most from (e.g. structured exercises, unstructured discussion, guests)? Explain your reasons.

... the least?

6. Make any additional suggestions for what we could change (add or delete) to make future groups more helpful to parents with a developmentally delayed child.

REFERENCES

Perske, Robert. New Directions for Parents of Persons Who Are Mentally Retarded, Abingdon Press: Nashville, Tennessee, 1973.

Foxx, Richard M. and Forehand, Rex. Two-part film and videotape entitled Parents and Children: A Positive Approach to Child Management and Behavioral Principles for Parents: A Discrimination Approach, Research Press: Champaign, Illinois.